

## **Visualizing Meaningful Assent: Interactive Media Design for Pediatric Advance Care Planning**

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### **Introduction**

Visual artists, writers, and performers widely agree that human beings have an innate need to create and to form expression from experience. The creative disciplines can agree at least on this one point, because they all routinely provide means for people to comprehend, evaluate, and share the intangibles of life through the act of making. Making provides a process of seeing, and indeed feeling, more completely. It generates insight through expression, both for the author and the audience. This capacity is leveraged to impressive degree in narrative medicine as well as in the many efforts of medical and medical humanities professionals to take advantage of the fine, literary, and applied arts to help themselves and/or their students more insightfully understand the complexities of perspective.

By similar account and yet in humble contrast, we offer here a new effort to use visual and interactive media to encourage deeper insight into patient needs and preferences in the context of pediatric care and research at end-of-life. To this end we are designing an interactive media application to elicit the values and preferences of pediatric patients, ages 7-12 years, in discussions regarding Phase I trial participation and care planning. The expression of desired experiences and values is central to a full understanding of how we might comport ourselves toward a dying child—foregrounding the child's best interest and benefit, thereby informing a process analogous to advance care planning in adult medicine. It is therefore the goal of our project to understand the child's individual experience of illness and life, and to enable expression how he or she wants to spend the last part of life. The use of interactive media is intended to help children conduct this personal end-of-life experience preference assessment and expression.

### **Background**

Interest in the use of advance care planning in pediatrics is growing because of the mandate set by the Institutes of Medicine in their report, "When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families" (2003). However, the means by which children participate in this process of developing advance directives that contain and express their priorities constitutes one of the major challenges and gaps that need to be addressed to advance ethical decision-making in pediatrics, and specifically ethical care at the end of life. The need to inventively address this challenge is most acute

for children with the developing capacity to participate in decisions regarding non-curative, high-risk trials (Phase I) and palliative care options, such as comfort care.

Teenagers, by contrast, are often able to participate in major medical decisions regarding their own care, placing them at one end of the pediatric decision making spectrum. On the other end of the spectrum are very young children, who are rarely cognitively capable enough to contribute to such decisions. Between these two extremes is a group of “middle” children whose ability to be involved meaningfully in such decisions is less clear. When a medical intervention or research trial has great potential to benefit a child, cure will be pursued regardless of such a child’s dissent, making his/her role in the decision making process less of a priority. When, however, a child is near the end of life and considering options such as enrollment on a Phase I trial and palliative care, involvement in the decision-making process is of the greatest personal relevance and ethical importance. In these latter situations the likelihood of benefit from a trial may be quite low, while the cost in terms of suffering and lost opportunities may be quite high. Therefore, it is ethically optimal to create an opportunity wherein children with the developing capacity to assent or dissent—those in the middle—can assess and express their goals, values and preferences, thus becoming part of deliberations about how their parents and caregivers might best attend their interests near the end of their lives.

Yet, regardless of capacity to assent or dissent, some children may not wish to state a choice. They may be too afraid or they may simply wish to be comforted by the fact that their parents are deciding. And sometimes children are so ill, they are unable to meaningfully convey assent or dissent. The fact that a child does not want to participate in the assent process does not exhaust the ethical considerations regarding enrollment of a child on a pediatric Phase I trial. The ethical justification of a Phase I trial must at least involve benefit to the child. The nature of this benefit certainly may come as a form of direct impact on the child’s tumor. However, benefit to health is not a realistic basis on which to predicate Phase I participation (Shah et al., 1998).

The process of advance care planning among adults is an effort to make clear one’s priorities, values, and preferences in anticipation of these times of difficult decision-making. An analogous process for children in this middle group will contribute to bringing their priorities into decision-making when potential benefits of being in a Phase I trial are being compared to standard care options, such as comfort care. This intention is based on the ethical requirements for meaningful assent, the evidenced needs of “middle” children to express their preferences regarding their care (Hinds et al., 2005), and the imperative to honor the dissent of patients to participate in non-curative experimental research.

### **Design Problem**

Common practice in art and design holds that the choice of any medium comes down to its fitness to purpose. Any number of media could be used to develop a pediatric-appropriate analogue to advance care planning, provided each medium invites the child into the decision-making dialogue and facilitates meaningful assent/dissent by generating a deeper understanding of the child’s individual experience of her illness and life. The formal and technical properties of interactive media, the communication techniques of visual design, the experience creation of interaction design, and the systematic software development process of designing with the intended users constitute a range of tools to visually and concretely frame complex experiences. Yet for all the capabilities and potential, it’s the specific problem criteria that determine whether or not this medium’s advantages are truly fit to purpose.

The matter of purpose, in this case, goes back to the key ethics-driven questions being asked—identifying core criteria for meaningful assent—which in turn create the design criteria that need to be met. Synthesized from the background discussion, these questions are

How does one elicit the child's preferences and bring him/her into the process of decision-making?

How can one help the child reach a decision consistent with his/her own priorities?

And, does the child have values such that participation in the options proposed by research physicians and other care team members would be of benefit in some way recognizable to the child as benefit?

While each question could be laboriously deconstructed to reveal specific methodological and formal design criteria, only the main points are presented here in order to focus more specifically on the opportunities visual and interactive media provide in meeting these specifications.

### Design Approach

Our present concept follows a comprehensive needs analysis with healthcare workers and months of prototyping potential solutions and then testing these prototypes for general “likeability” with healthy children. Identifying trends in favored interaction motifs, we created the revised prototype, shown below, which is explicitly designed for the child to express and evaluate, using the rudimentary concept of proportion, preferred interests, wishes, or actions. The patient can label each section, select colors, and grab handles to expand or contract each area. Intended as a regular, iterative activity preceding and extending throughout the patient care experience, each time-based expression offers an opportunity for patients, parents, and care team members to discuss the results together. These expressions, and their resultant discussions, carried across difficult deliberations, form one means to bring the pediatric patient more fully into the process of decision-making via a creative analogue to adult advance care planning.





While the patient is provided with a predetermined platform, in this case a website, the flexibility of the medium allows the child to create a succinct visual statement in which he/she determines what's said, how it's emphasized, how long it remains a priority, and who sees it. And because this is ultimately about decision-making, the patient concretely experiences the consequences of electing to emphasize, for example, a Phase I trial. The pie chart conveys time as finite. As one area is enlarged, its neighbors are automatically reduced. Whether or not the patient has formally engaged in assent by offering a yes or no answer, expression of the weight of importance of the items selected enhance the opportunity for parents and caregivers to recognize the child's priorities. Participation in a Phase I trial then supports what the child sees as a beneficial use of his/her time, or just the obverse.

Ultimately, the fitness to purpose for this medium depends on how well it meets the most fundamental requirement for assent: soliciting the minor's willingness or unwillingness to participate in the actions proposed by parents, healthcare providers, and physician researchers. Whether such insight is provided by this particular act of making for this particular group of patients is the focus of our forthcoming research.

### Limitations

This tool is intended to state and evaluate a complex set of experiences, concerns, and priorities, synthesizing these down to a single snapshot or series of snapshots. Yet behind and between these succinctly visualized emphases we require a continuum of care informed by an on-going narrative of experience. No medium can succeed without a culture to adopt, implement, deploy, and sustain it. The final, validated tool would need to be implemented into practice via a comprehensive palliative care program and within a hospital with sufficient Information Technology staff to periodically monitor and update the application.

Furthermore, software applications are more successful when the designers have access to "end-users" at each step of the design and development process. However, our "users" are members of a protected population of terminally ill children. We have adjusted to this limitation by creating a process that engages healthy children and non-terminal patients for each step prior to the final pilot implementation and efficacy studies.

## Conclusion

Our project is aimed at facilitating an advance care planning process, analogous to that in adult medicine, for children under age thirteen at the end of life and facing Phase I research trial and palliative care decisions. The resulting interactive multimedia experience will allow children with the developing capacity to assent to express their priorities, values, and needs in a way that impacts the decision-making process regarding Phase I trials, comfort care, and other important decisions when curative therapy is no longer a viable option. It is therefore the goal of our project to employ interactive media as a means to elicit a deeper understanding of children's experiences of illness and life, and to enable them to express how they want to spend the last part of their lives. The desired outcome is an advance care planning process in which children meaningfully impact the establishment of their own life plans so that medical interventions will be compatible with their individual priorities.

## References

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Additional concepts included in this paper are drawn from the conference paper "Medicine, Design and Ethics: Bridging Disciplines to Enable Meaningful Assent in Pediatric Phase I Trials," delivered by Raymond Barfield, MD, PhD, Carson Strong, PhD, and Michael Schmidt, MGD, at the 2007 annual meeting of the American Society for Bioethics and Humanities.

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